Family Involvement in Decision Making for People with Dementia in Residential Aged Care: A Systematic Review of Quantitative Literature

Abstract

Aim. Ensuring older adults' involvement in their care is accepted as good practice and is vital, particularly for people with dementia, whose care and treatment needs change considerably over the course of the illness. However, involving family members in decision making on people's behalf is still practically difficult for staff and family. The aim of this review was to identify and appraise the existing quantitative evidence about family involvement in decision making for people with dementia living in residential aged care.

Methods. This Joanna Briggs Institute (JBI) meta-synthesis assessed studies that investigated involvement of family members in decision making for people with dementia in residential aged care settings. Whilst quantitative and qualitative studies were included in the review, this paper presents the quantitative findings. A comprehensive search of 15 electronic databases was performed. The search was limited to papers published in English, from 1990 to 2013. Twenty six studies were identified as being relevant; ten were quantitative, with one mixed-method study. Two independent reviewers assessed the studies for methodological validity and extracted the data using the JBI Meta Analysis of Statistics Assessment and Review Instrument (JBI-MAStARI). The findings were synthesised and presented in narrative form.

Results. The findings related to decisions encountered and made by family surrogates, variables associated with decisions, surrogates' perceptions of and preferences for their roles, as well as outcomes for people with dementia and their families.

Conclusions. The results identified patterns within and variables associated with surrogate decision making, which all highlight the complexity and variation regarding family involvement. Attention needs to be paid to supporting family members in decision making in collaboration with staff.

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Keywords: decision making; dementia; family; residential aged care; systematic review

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Background

Ensuring older adults' involvement in their healthcare and in decision making is now recognised as a central concern in the provision and assessment of care giving services.[1] As a result, attention has been paid within nursing literature to care recipients' participation in planning and decision making in a range of settings, including hospitals, residential homes, and community care.[2,3] Involving a person with dementia, however, becomes increasingly difficult in the context of the declining cognitive functioning that is attendant with this illness. Progressive cognitive decline necessitates including a person's nominated surrogates (frequently relatives), who can support the person's values and wishes being taken into account in care provision.[4]

Internationally, areas of legislation and policy highlight the role of proxy decision makers as important to care decision making for older people, and there is widespread legislative provision (for a comparison, see http://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/Legal-capacity-and-proxy-decision-making) for assigning decision making power to a proxy (Enduring Power of Attorney and Guardianship, for example). In Australia, where the authors of this paper are located, the Aged Care Standards recognise the centrality of the resident's representative in contributing to care and decision making. Reference to the resident and 'his or her representative' are articulated throughout the document.[5] However, legal processes which could support decision making at end of life, for example the appointment of a substitute decision maker, differ across Australian states and territories.[6] Similarly, the United Kingdom's Care Quality Standards make reference to "someone acting on (the resident's) behalf", including in care discussions[7] and Northern Ireland's Nursing Home and Residential

Care Home Minimum Standards make frequent reference to “residents and their representatives” being informed, consulted, and involved in decision making and care planning, among other decisions in the facility.[8, 9] In the United States, the Federal Requirements for Long Term Care Facilities[9] commonly makes reference to “the resident or their representative”, the “legal representative”, or “family member” in regard to information, consent, and care planning. Other countries similarly, both implicitly and explicitly, refer to representatives, including family, being informed and involved in planning and decision making. However, the enactment of these standards is not consistent across contexts.

There have also been attempts to develop best practice approaches to involving family members in the care of older people in residential care. In Australia, for example, participation of family members in the care of older people is also highlighted in the Palliative Approach Guidelines for RAC and Community.[10, 11] Further, the recent development of consumer focused documents in Australia which highlight the role of family members and proxy decision makers in contributing to care decisions for planning for end of life with dementia is a good example of the growing policy context which supports the involvement of proxy decision makers.[6] Whilst the role of proxies including family members is supported in these policies and regulations, there is no consistent approach.

Despite the varying legislative and policy context, family members do act as both sources of information, as well as surrogate decision makers in this context, and the participation of family members in care is considered an essential part of contemporary care.[12] The important role family members can play in this process has received considerable attention within nursing literature. This has highlighted the range of decisions in which family members are involved.[1] Family members can face decisions in areas ranging from lifestyle choices[13] to end-of-life (EOL)

care.[14] Family involvement in decision making can be challenging and complicated, despite its importance and benefits. A range of factors influences decision making and the effectiveness of the decision making process, notably, communication and relationships between staff and family members, and family knowledge and understanding of care issues, illnesses, and their relatives' wishes.[15] Moreover, once decisions have been made, family members can still face challenges in implementing decisions on behalf of their relatives, or report concerns about implementation and their influence over the final outcome.[16] Despite their role being supported in legislation and policy, and despite being required to comply with codes of practice in regard to their role, it has been suggested that little information, advice, and support is available to proxies, and that they face barriers relating to policies and practices which work against them.[17] While the United Nations Convention on the Rights of People with Disabilities emphasises the importance of support in decision making,[18] little support is available in reality to those working with and on behalf of their relatives with dementia.

In the specific case of older adults with dementia and the central role that family members can play in proxy decision making, it is vital to consider what factors influence family decision making, particularly in terms of staff-family interactions. Further, it is important to assess what factors shape and hinder this process of shared decision making, so as to improve both staff and family members' understanding of what the role entails, and how it can be facilitated, and thus improve the provision of care to people with dementia in the future.

The review

Aim

The aim of this systematic review was to identify and appraise the existing knowledge about family involvement in decision making for people with dementia living in residential aged

care. Whilst the complete review included both qualitative and quantitative studies,[15] this paper presents the findings from the quantitative component. The review questions were:

• Who are the decision makers for people with dementia living in residential care?

• What is the experience of decision making for family members in the residential care setting?

• What are the barriers or facilitators to decision making by families?

• What is the impact of decision making processes on family members?

• What is the impact of collaborative decision making with family on the person with dementia?

• What processes or strategies do family decision makers use?

Review design and search methods

A systematic review was conducted following the guidelines of the Joanna Briggs Institute (JBI) for systematic reviews. This involved searching for papers that met the inclusion criteria, assessing the papers for methodological quality using the JBI Meta Analysis of Statistics Assessment and Review Instrument (JBI-MAStARI), and then synthesising the findings from the selected papers.

The search strategy aimed to find both published and unpublished studies. An initial limited search of MEDLINE and CINAHL was undertaken followed by an analysis of the words contained in the titles and abstracts, and of the index terms used to describe the article. A second search using all identified keywords and index terms was then undertaken across all included databases. Thirdly, the reference lists of all identified reports and articles were searched for additional studies. Studies published in English, between 1990 and 2013, were considered for inclusion in this review.

The search was conducted using 15 databases: CINAHL; Medline; PsycInfo; ISI Web of Science; PubMed; Embase; APAIS-Health; Ebsco Health Source; Sociological abstracts;

ProQuest digital dissertations; PsycArticles; ProQuest academic research library; Google Scholar; Mednar (excluding Google Scholar); and CareSearch. Search terms are detailed in Table 1.

The review included studies regarding people with dementia living in residential aged care, their families, and care staff, and focusing on family involvement in decision making in this context. Only studies which included a minimum of 70% participants with dementia in residential care (nursing home, NH) settings were included. No restrictions were imposed on the definition of "dementia", diagnosis, stage or severity, or on the age of participants. Care staff included staff in all roles providing care to people with dementia in residential aged care. Decision making included decisions relating to the physical, psychosocial, spiritual, and emotional domains of care; the review explicitly excluded studies that were solely concerned with decisions about whether to enter residential aged care or decisions regarding financial matters. The review considered both experimental and descriptive study designs including randomized controlled trials, non-randomized controlled trials, quasi-experimental, before and after studies, prospective and retrospective cohort studies, and cross sectional studies.

Search outcome

Initially, 1029 qualitative and quantitative studies were identified after the exclusion of duplicates. Following a review of the titles and abstracts, full text was retrieved for 153 papers and these were reviewed by two independent reviewers against the inclusion criteria detailed above. Twenty six papers were included in the full mixed method review (Figure 1). This paper focuses on the findings of the 11 quantitative papers (including one mixed methods study).

Quality appraisal

Papers selected for retrieval were assessed by two independent reviewers for

methodological quality using standardised critical appraisal instruments from JBI-MAStARI (Figures 2–4). All nine descriptive/observational studies (including one mixed method study) met five key criteria as identified by the reviewers (Figure 2). One study[19] was excluded as it did not meet criterion 2 (Were criteria for inclusion in the sample clearly defined?). One randomised controlled trial[20] met the six key criteria identified (Figure 3). One cohort study[21] met the five key criteria identified (Figure 4). None used a random sample, although the RCT used random allocation, and whilst confounding factors were generally identified, these were not often discussed or addressed explicitly. Overall, the standard was judged sufficient for inclusion.

Data abstraction and synthesis

Data were extracted from papers using the standardised data extraction tool from JBI-MAStARI. The data extracted included details about the interventions, populations, study methods, and outcomes of significance to the review questions. It was not possible to pool data in statistical meta-analysis using JBI-MAStARI. Therefore, the findings are presented in narrative form in five key areas: Decisions encountered by family surrogates; Variables associated with treatment decisions; Reasons or basis for decisions; Collaborative decision making process; and Outcomes of decision making.

For the purposes of clarity and brevity, this paper focuses on the quantitative evidence from this review. This evidence presents one facet in explaining family decision making for people with dementia in residential aged care, and needs to be considered in conjunction with the qualitative evidence, as presented elsewhere [15]. However, it is additionally useful to consider the quantitative evidence in its own right, in order to identify key statistics, variables and outcomes related to decision making.

Results

An overview of included studies is provided in Table 2. Studies used a range of methods; most used questionnaires, while some included review of charts or death certificates. Data analysis included a range of statistical techniques; however, the most common presentation of data used percentages and Chi-square. Two studies reported on interventions, most reported data relating to actual decisions made by family and two used hypothetical scenarios. Participants included family members, physicians, and other staff including nurses. The type and depth of description of participants (e.g., age, sex, socioeconomic status, educational and ethnic background, and co-morbidities) varied, making it difficult to compare and draw conclusions based upon sample characteristics.

Decisions encountered by family surrogates

Five studies reported on the types of decisions encountered by family proxies and the choices made. Two studies reported on the particular types of decisions encountered in the residential care context. In a prospective cohort study, Givens *et al.*[21] found that 38% of the Healthcare Proxies (HCPs) had made at least one decision during the study period, relating to eating and drinking problems (27.2%), treatment of infections (20.7%), transfer to hospital (3.9%), pain (12.9%), shortness of breath (8.2%), behavioural issues (6.9%), cancer (3.0%), or other issues (17.2%). Similarly, Maust, Blass, Black, and Rabins[22] reported decisions faced by their sample related to whether to admit to hospital (73.2%), agree to surgery (46.3%), tests (69.1%), X-rays (57.7%), treatment for pneumonia (34.1%), or treatment for other infections (53.7%), the use of a feeding tube (46.3%), and the use of a respirator or ventilator (38.2%).

Contrasting findings were reported for what surrogates chose. In Maust *et al.*'s[22] study, for example, most of those faced with the decision agreed to hospitalisation (59%), surgery

(42%), tests (63%), X-rays (62%), and treatment for pneumonia (36%) and other infections (59%), but most who were faced with the decision did not agree to use of a feeding tube (52%) and the use of a respirator or ventilator (43%). Some contrasting findings were reported by Pasman *et al*.,[23] however, who investigated advance care plans and surrogate decisions. These were more often to forgo (64%) than to start treatment (44%). It was more common to forgo than to agree to hospitalisation (48% vs 20%), artificial nutrition and hydration (ANH) (42% vs. 20%), resuscitation (42% vs. 14%), and life prolonging treatment generally (29% vs. 18%). For antibiotic treatments, conversely, it was more common to agree to, than to forgo (28% vs. 3%), instigation. The most common decisions made (either starting or forgoing) related to admission to hospital, ANH, and resuscitation. De Boer, Droes, Jonker, Eefsting, and Hertogh,[24] investigating advance directives (ADs) for euthanasia, found that in 16 of 110 cases, relatives wanted adherence to the directive; a similar (unspecified) number were reported to want non-adherence. In a small number of cases there was disagreement between relatives or relatives had no opinion at all; however, more than half wanted some limitation on life-sustaining treatments. Relatives' wishes were cited by 4.5% of physicians as a main reason for not adhering to an AD. Finally, taking a different approach, Cogen, Patterson, Chavin, Cogen, Landsberg, and Posner[25] explored hypothetical treatment decisions. They found that 14.7% of surrogates chose treatment and 11.8% chose no treatment in all the hypothetical treatment scenarios. Nearly two thirds agreed to hospitalisation for pneumonia, three quarters to ICU admission for worsening sepsis, 43.6% to mechanical ventilation for respiratory failure, 35.4% to tube feeding, and 31.6% to cardio-pulmonary resuscitation (CPR), which was the least accepted intervention.

Each of the studies, therefore, focused on medical or treatment decisions. Although a lack of consistency in measurement made it difficult to draw conclusions on the most common

decision types faced, some similar decisions were faced by surrogates across studies (e.g., hospitalisation, breathing issues, eating and drinking problems, and treatment for infections). However, agreement to aggressive treatments varied.

Variables associated with treatment decisions

Five studies reported variables that were associated with the treatment decisions made by surrogates, which related to surrogate characteristics, characteristics of the person with dementia, and other context-specific factors.

Several characteristics of both surrogates and patients have been found to be related to decisions made by surrogates. Cogen *et al.*,[25] for example, found a positive correlation between male sex of surrogates and the decision to provide treatment ($r=.21$, $p<.05$). There was no significant effect of surrogate age or education, or previous experience with an intervention. Teno *et al.*[26] found that the religious beliefs of the person with dementia and their family members influenced the decision to insert a feeding tube in 13.6% of cases. Kwok, Twinn and Yan[27] presented the scenario of critical illness or coma to 51 Chinese family caregivers. They found that decisions to forgo or accept life-sustaining treatments were related to whether the person resided in an NH, a higher education level among family caregivers, and financial burden related to the illness (r ranged from 0.277 to 0.339, $p < 0.05$). In subsequent regression analysis of this data, financial burden predicted a decision to forgo antibiotics in both scenarios (critical illness, OR 2.06, 95% CI 0.98–4.34; irreversible coma, OR 2.01, 95% CI 1.09–2.69), and to forgo tube feeding in irreversible coma (OR 2.03, 95% CI 1.11– 3.71). Their relative living in an NH predicted caregivers' decision to forgo artificial ventilation in the case of a critical illness (OR 5.33, 95% CI 1.08–26.36).

In Maust *et al.*'s[22] study, decisions about providing treatment were related to a range of surrogate and resident variables. Non-provision of treatment was associated with the surrogate decision maker being white and older ($p = 0.022$ and $p = 0.046$, $df = 98$ respectively), the resident being white ($p = 0.010$) and the resident having a higher level of education ($p = 0.041$, $df = 1$). It was also related to worse quality of life as rated by surrogates ($p = 0.004$, $df = 94$), more frequent contact with nurses ($p=0.031$, $\chi 2$, $df=1$), attending support groups for dementia caregivers ($p=0.048$, $\chi 2$, $df=1$), and presence of a Do Not Hospitalise (DNH) order. The authors also identified co-morbidities among residents; of the seven co-morbidities, there was a trend for less treatment for those with chronic obstructive pulmonary disease (COPD) or active heart disease ($p<0.10$, $df=1$ for both by $\chi 2$, ns). Conversely, those admitted to the NH as a result of medical complications were more likely to have received treatment ($p = 0.050$, $df = 1$). In regression analysis, the resident being white and male predicted a decision not to provide treatment (OR = 14.60, CI 1.72–123.77, $p=0.014$ for white residents and OR = 3.09, CI 1.25–7.67, $p=0.015$ for male residents). In a second regression model, being white (OR 9.53, CI 1.09–83.58, $p=0.042$) and the presence of a DNH order (OR 8.17, CI 3.10–21.51, $p= <0.001$) predicted not providing treatment. Contrary to Teno *et al.*'s[26] findings, however, there were no significant relationships with any of the seven questions relating to religious and spiritual beliefs (p ranging from 0.650 to 0.981, $\chi 2$, $df=1$). Prior experience in making healthcare decisions for other adults also was not related to treatment decisions ($p=0.677$, $\chi 2$, $df=1$). The authors concluded that treatment decisions related mainly to characteristics of the person with dementia, rather than characteristics of their decision maker, or of the illness, or other contextual factors.

The decisional context and provision of information, however, been found to be important in decision making in other studies. In their study of hypothetical treatment scenarios

described earlier, Kwok *et al*.[27] found that caregivers were more likely to decide to forgo treatments in irreversible coma than they were in critical illness [CPR (χ^2 = 9.22, d.f. = 1, p < 0.01), artificial ventilation (χ^2 = 15.59, d.f. = 1, p < 0.01), tube feeding (χ^2 = 7.74, d.f. = 1, p < 0.01), and antibiotics (χ^2 = 6.61, d.f. = 1, p < 0.01)]. After they received information about the clinical outcomes of CPR and tube feeding, four caregivers (8%) changed their minds about CPR, deciding to forgo this treatment in the event of critical illness, and six (12%) changed their minds in the coma scenario; 8% changed their minds about tube feeding, deciding to forgo treatment in the case of critical illness, and 14% in the case of coma. The changes were statistically significant for the hypothetical coma scenario (p < 0.05 and p < 0.01 for CPR and tube feeding respectively). Thus, both the illness context and the level of information provided about the implications of treatment affected decisions.

One study reported the results of a randomised controlled trial of a structured decision aid providing information about dementia, feeding options, and the surrogate's role in decisions.[20] The study found use of the decision aid intervention to be associated with treatment choices among surrogates: increased use of assisted oral feeding techniques (dysphagia diet, p = .04) and a trend toward greater use of specialised feeding assistance (p = .08). Weight loss in the residents was also less common in the intervention group (p = .01); however, mortality was similar between groups. The intervention was also associated with higher knowledge scores (M = 16.8 intervention vs. 15.1 control, p < .001) and fewer expected benefits from tube feeding (2.3 vs. 2.6, p = .001). The authors concluded that the decision aid improved the quality of decision making.

Surrogate characteristics, characteristics of the person with dementia, as well as other context-specific factors, such as those relating to the illness or treatment, have been found to be

important; however, there is little consistency between studies regarding these findings. This variation in measurement and findings meant that more specific overall conclusions, with regard to factors related to decisions, could not be drawn.

Reasons or basis for decisions

Four studies reported findings relating to the reasons or basis for the decisions made by surrogates, beliefs and knowledge among surrogates about dementia and various treatments, and knowledge and use of the wishes or preferences of the person with dementia.

Three studies reported varying levels of knowledge about, and use of, the wishes of the person with dementia. In their hypothetical scenarios, Cogen *et al.*[25] found that very few surrogates based decisions solely on past statements by the person with dementia. Decisions did not involve any previous statements by the person with dementia in 69.7% of cases, 30.6% based their decisions on their own views, and 5.1% on assumptions as to what the resident would choose, with 61.2% using a combination of factors. In Kwok *et al.*'s[27] sample, 8% of family caregivers had discussed CPR and tube feeding with their older relatives, and 4% of these had expressed their own wishes about future treatment. Kwok *et al.*[27] reported that 72% of their sample considered the patient's wish to be of great or some importance in decision making on life-sustaining treatments, with 28% considering it to be of no importance. In contrast, 96% considered the doctor's opinion to be of great or some importance, 92% considered their own opinion to be of great or some importance, and 75% considered other family and friends' opinions to be of great or some importance. Somogyi-Zalud, Likourezos, Chichin, and Olson,[28] investigating decisions about tube feeding, found that 10% of surrogates had discussed tube feeding with the person with dementia, and only 8% reported that the person with dementia had ever stated their wishes. Nearly a quarter of surrogates thought the resident would agree to the

feeding tube; however, 42% reported that they did not know. A quarter (25%) of surrogates agreed to a feeding tube despite believing the person themselves would have chosen not to use one and three of the fifty residents received ANH despite stating in their living will that they did not want this to occur.

Although they did not relate this information statistically to decision making, several studies reported beliefs and knowledge among surrogates about dementia and various treatments or interventions. In Kwok *et al*.'s[27] study, caregivers did not have high levels of knowledge about life-sustaining treatments, with 59% and 26% unable to name any feature of CPR and tube feeding, respectively. None could name more than three features of CPR and half could not name more than three features of tube feeding. Cogen *et al*.[25], on the other hand, found that all or most of their sample could correctly identify the function of a gastrostomy tube and ventilator, and the role of CPR. Most had experience of at least one intervention. In Givens *et al*.'s[21] study, 83.6% of surrogates reported that they understood the medical aspects of advanced dementia and close to three quarters reported that they believed dementia was a terminal illness. It is important to note in the context of these findings that increasing acceptance and understanding of dementia as a terminal illness is relatively recent in the context of this review, a change which might be reflected here. Somogyi-Zalud *et al*.[28] reported that around half of the surrogate decision makers felt they were given enough information to make the decision about tube feeding, and a third reported feeling comfortable making the decision. Surrogates' leading concern was the medical complications from tube feeding. However, most felt that their concerns, including these issues, were adequately addressed by staff. Despite this being a principal concern, more than half of the surrogates reported not being worried about medical complications. The majority also reported not being concerned about a range of other potential outcomes.

Knowledge about dementia, about co-morbid illnesses and treatment options, and knowledge about the person with dementia's own wishes and preferences therefore varied. Notably, however, even in cases in which the surrogate decision maker was aware of their relative's wishes, they did not necessarily make decisions in line with these.

Collaborative decision making process

Nine studies reported findings relating to different dimensions of the collaborative decision making process. These related largely to the dynamics of communication, collaboration, and relationships between staff and family. The studies explored what discussions took place, who discussions were with, and whose perspectives influenced decision making.

Although the surrogate is the main decision maker, other relatives may also be involved. Pasman *et al.*[23] found that existing advance care agreements were most often made with the children of the person with dementia; however, agreements were also reported with other family members and the patient's partner. In Somogyi-Zalud *et al.*'s[28] study, other family members participated in the decision in half of the cases.

The studies also indicated that the extent to which decisions involved surrogates varied. In Kwok *et al.*'s[27] sample, five caregivers (9.8%) reported being asked by doctors to discuss CPR and tube feeding. Teno *et al.*[26] found that nearly 11% of people with dementia had a feeding tube inserted, with no discussion about managing eating problems in over half of the cases. For 13.7% of people who were given a feeding tube, there was no prior discussion with a healthcare provider; in over 90% of these cases, the family believed there should have been a discussion. Just over 11% of family members of residents with a feeding tube reported feeling pressured by the physician to agree. Pasman *et al.*,[23] however, found that nursing home physicians (NHPs) discussed the decision to start ANH with the patient's family in 99% of the cases and nurses

reported discussing this with family in 88% of the cases. Family reported discussing the decision with physicians and nurses less than did these professionals themselves; however, in most cases, there were discussions involving the NHP, family, and a nurse. While most physicians, nurses, and family members felt that family had a considerable degree of influence on the decision, there were discrepancies between groups in the degree of influence each thought family had, and who made the decision. Most reported that there was consensus. De Boer *et al*.[24] similarly found that nursing home policy regarding euthanasia was discussed with relatives or representatives of the resident 95.5% of the time. Discussion was most often initiated by the physician, the resident's representative, other relatives, or other healthcare professionals. Discussion was initiated by the resident themselves in only 4.5% of cases. Cornegé-Blokland, Kleijer, and Hertogh[29] reported that physicians felt pressured to prescribe antipsychotic drugs for behavioural and psychological symptoms of dementia in 17% of cases; in most of these cases, the pressure was from nurses, and much less frequently from family. The family's opinion carried the most weight in decisions in 5.4% of cases, with physicians' and nurses' opinions having most influence most of the time. The majority of caregivers gave consent for the prescription (despite less than half feeling sufficiently informed about the side effects), 19% were opposed, and 16% were not consulted. A large proportion felt their opinion was weighted sufficiently. In Hanson *et al*.'s[20] trial, surrogates in both the intervention and control groups reported that they were somewhat or very involved in decisions about feeding treatments ($p = .18$). Over the following three months, however, those in the intervention group were more likely to discuss treatments with a physician, nurse practitioner, or physician's assistant than were controls ($p = .04$). There was no difference in discussions with other staff.

Some papers used measures of satisfaction to evaluate decision making. Pasman *et al.*[23] found the majority of family reported being satisfied with the openness in the process, the information received, and the opportunity to give their opinion. A quarter were dissatisfied with the short time frame for decisions. In Givens *et al.*'s[21] prospective cohort study with surrogates, the vast majority agreed or strongly agreed that they were satisfied their opinion was important, that they felt the right choice was made, that they were satisfied with the decision, that they had enough input, and that they received enough information about the problem and treatments. Ten per cent felt they relied too much on the doctor's opinion. Only half had spent at least 15 minutes discussing ADs with the provider at admittance. The majority also rated as excellent or very good the treatment decision, the primary care provider's personal interest, the primary care provider's attention given to their opinion, the primary care provider's reassurance and support, the amount of information about the problem and treatments, the explanation of treatments, the time spent with the primary care provider, and the amount of help from the primary care provider in making the decision. The authors concluded that there was greater satisfaction with the decision itself than with the process. Proxies were least satisfied with the perceived involvement of the primary care provider: the provider's reassurance and support, the amount of information about the problem and treatments, and the time spent with the primary care provider (all less than 20% rating as fair or poor). A number of variables were related to satisfaction scores ($p = .1$): the proxy not being the resident's child, living with the resident before admission, visiting more than seven hours per week, higher scores on the SF-12 mental subscale, focus of treatment on comfort care, the resident living in a special care unit, longer length of stay, greater resident comfort, and having a DNH order. In the regression model, the proxy not being the resident's child (beta =

7.10, p = .02), the resident living in a special care unit (beta = 9.48, p = .002), and higher comfort score (beta = 0.49, p = .004) were associated with higher satisfaction scores.

Rurup, Onwuteaka-Philipsen, Pasman, and Ribbe[30] explored attitudes towards ANH, ADs, hastening the death of people with advanced dementia, self-determination and euthanasia, and policy regarding forgoing treatment. They found that physicians, nurses, and relatives agreed on many issues relating to EOL decision making; however, there were several significant differences between the attitudes of family members and those of physicians and nurses. For example, all agreed that "On admission, the treating physician should routinely ask the patient or the patient's family about any possible wishes concerning the end of the patient's life". However, more relatives (78%) than nurses (61%), and more nurses than physicians (44%) fully agreed with this. Similarly, 78% of the nurses and 88% of the relatives, but only 37% of the physicians agreed that "An advance directive should always be followed". Some of these views related to religious beliefs of the surrogates or the person with dementia, pain and comfort of the person with dementia, presence of an AD, and the relationship of the family surrogate to the person with dementia. For example, of the 10 patients who had an advance directive, nine relatives agreed that "An advance directive should always be followed".

Thus the findings from these studies suggested that whilst the surrogate decision makers themselves, and other family members, may be involved in discussion and decisions, the extent to which decisions are discussed with surrogates, and involve surrogates, varies considerably. Surrogates' level of satisfaction with the decision making process can also vary, with particular issues relating to time pressures on family and the amount of involvement by primary care providers.

Outcomes of decision making

Four studies provided data on the outcomes experienced by people with dementia and their surrogate decision makers as a result of the decision and the decision process.

Two intervention studies explored aspects of comfort and confidence in decision making. In Hanson *et al.*'s[20] trial, their decision aid was associated with significantly lower decisional conflict ($p < .001$) and significantly greater reduction in decisional conflict compared with a control group ($p < .001$). Kwok *et al.*[27] found some difference in level of comfort with decisions, reporting that surrogates were more comfortable forgoing than choosing treatments in the hypothetical case of coma ($\chi^2 = 5.303$, 4.293, & 4.097, d.f. = 1, $p < 0.05$ for CPR, artificial ventilation and antibiotics respectively). No results were provided for the critical illness scenario. However, unlike Hanson *et al.*'s[20] study, their intervention – information about the clinical outcomes of CPR and tube feeding – did not affect certainty or comfort in decision making, even though some changed their decision following the intervention (no values provided).

Two studies identified outcomes for the person with dementia; both focused on feeding tubes. In Somogyi-Zalud *et al.*'s[28] sample, complications of tube placement were tube displacement, vomiting, aspiration pneumonia, clogged tube, tube site infection, and recurrent fever. After six months or more following tube placement, just over half of the surrogates rated the resident's quality of life as poor or extremely poor with a quarter rating it as good or very good. Just over half agreed that tube feeding changed the resident's quality of life, with 48.1% saying it was improved or much improved, and 51.8% saying it was worse or much worse. However, most reported that tube feeding was of overall benefit and the majority said they would repeat the decision; 14% would consider removing the tube. Thus, most were satisfied despite seeing no improvement in quality of life. In Teno *et al.*'s[26] study, outcomes reported were

improved quality of life, the patient appearing to be bothered by the tube, being given medication or tied down to prevent them from pulling at the tube, or being sent to the emergency department because of a problem with the tube. At the time of death, feeding tubes had been stopped in 38.5% of cases; in two thirds of these, death occurred within a week. A quarter of the family members reported that they were distressed during this time. Family members whose relative died with a tube were less likely to rate EOL care in the last week of life as excellent (adjusted OR = 0.42, 95% CI = 0.18–0.97). Similar to Somogyi-Zalud *et al.*'s[28] findings, just under a quarter of the decision makers reported regret about their decision, whereas the majority reported it was the right decision.

For family members, therefore, comfort and confidence in decisions may potentially be increased through use of a decision aid; however, the results for another information intervention were not as promising. For the person with dementia, the outcomes from interventions, such as tube feeding, may not be positive; however, decision makers report being happy with the decision.

Discussion

This review aimed to synthesise the evidence on family involvement in decision making. A total of 11 papers reporting a range of aspects of decision making were included. The review aimed to address a number of questions around family decision making. The papers identified considerable variation in the decisions made by proxies, the degree to which proxies are involved in decision making, their experience of, and satisfaction with, decision making, their knowledge, and their incorporation of the wishes of their relative. Various factors were associated with decisions. Findings suggest that family members are not always involved in, or consulted, in decisions, do not always know their relative's preferences, and do not always give great weight

to these preferences in decisions. Further, level of comfort or confidence in their decisions may vary; however, even when positive outcomes are not evident for the person with dementia, the decision maker may still report satisfaction with the decision.

The review questions asked about who makes decisions for people with dementia in residential care, the family's experience of decision making in this context, and barriers or facilitators to decision making by families. In the broader literature, the decisions in which family members and surrogate decision makers are involved are diverse, including decisions relating to feeding problems, infections, pain, dyspnea, behaviour problems, transfer to hospital, co-morbid conditions such as cancer, and other complications,[21] EOL care,[14,31] or leisure and lifestyle.[13] The studies included in this review focused on treatment or EOL decisions and revealed that similar treatment decisions were faced by surrogates across the studies; however, the extent to which they were willing to agree to aggressive treatments varied.[22,23,25] The importance of involving surrogate decision makers in these key decisions, therefore, was further highlighted in the review; the range of decisions faced by surrogates and the variation in their agreement with treatment signals the complexity of this decision making and the importance of ensuring that assumptions about preferences are not made.

The studies addressed the collaborative decision making process including the dynamics of communication between staff and family, what discussion took place, and who was involved in the process. The studies indicated that the extent to which discussion and decisions involving family varied; some found it to be limited,[26,27] whereas others reported considerable involvement[23], and two studies also indicated involvement of family members other than the surrogate decision maker.[23,28] Thus, family members were frequently, but not always, involved in decision making. Studies reported different degrees of family members' satisfaction with their

experience of decision making, including their own involvement in the decision making process, as well as the information they were given as part of the process, and time allocated for decision making.[21,23] This variation suggests that family involvement is not consistently used in decisions, is not consistently supported and facilitated, and is not consistently experienced as satisfactory by family members. Overall, these findings suggest wide variation in whether, and to what extent, this decision making process actually occurs in the residential setting. This is cause for concern because routine and effective involvement of family in care decision making is critical if care is to be configured in ways that are consistent with a palliative care approach; an approach most appropriate for individuals with a terminal illness like dementia.[32] Indeed, the involvement of family members in care decision making is seen as central to implementing a palliative approach to care.[33] As many of the treatment issues identified in the papers reviewed here relate to late stage dementia and end of life, this is a key concern for practice.

The studies highlighted the importance of information and communication between families and staff, and the inconsistency in this communication relating to treatment decisions. These findings reflect those of other studies which have highlighted staff-family communication and relationships as important in facilitating family carer involvement in decision making.[34,35] The time spent with physicians and other care staff and discussion with these staff was also a key area impacting upon the effective involvement of family surrogates identified in the qualitative component of this review, the results of which are reported elsewhere.[15] The review findings also reflect other studies, such as that of Kelley *et al*.,[36] which reported family concerns about the influence they had over the outcome of planning. Attention to the level and effectiveness of staff-family communication and interaction is therefore warranted.

Additional literature on staff-family communication suggests that both family[37,38] and staff members[39,40,41,42] have reported difficulties with communicating about the resident with dementia, with each adopting strategies that paradoxically may reduce communication. Gaps in knowledge about dementia and its trajectory contribute to this difficulty.[43,44,45] Ways to ameliorate poor communication have been proposed in the literature on this topic. In instrumental terms, appropriate settings, timings, and preparations for meetings or communication are necessary,[46,47] as is a shared understanding of the nature and trajectory of dementia. Stirling *et al.*'s[43] trial of a discussion tool to facilitate communication between staff and family members of people with dementia included both information about dementia, as well as "how to" and "what to say" examples and scripts. The tool enabled staff to increase the amount of knowledge of the nature and trajectory of dementia shared by formal and informal caregivers. As well as increasing the confidence of staff to engage with family members, the tool was found to increase family members' sense of engagement with facility culture. Trust, involvement, and "keeping the family happy" are elements promoted by the recognition and valuing of each other's knowledge and expertise.[42] Thus, a further means of engaging families more collaboratively in aged care facility culture and in the ongoing decision making about people with dementia is via the valuing of family members' biographical knowledge of the person with dementia and their care needs. Such knowledge enables staff to see a whole person,[48,49] rather than a "patient", and is thus valuable in person-centred approaches. In addition, the use of such biographical knowledge by staff empowers families "as legitimate experts"[50] who can continue to care, and who are more able to "influence and intervene" (p. 323).

Whilst the barriers to or facilitators of decision making by families were addressed in the

qualitative component of the review, and some barriers and facilitators to decision making are implied in the findings of this review (e.g., those relating to areas of lower satisfaction with the process), the quantitative studies did not explicitly address barriers and facilitators. They did, however, indicate that treatment decisions were related to surrogate characteristics, characteristics of the person with dementia, and other context-specific factors.[29,20] Whilst the inconsistency in measurement and in findings precluded any broader conclusions about such relationships, these findings highlighted the potential for further research to better understand the relationships between certain characteristics and decision making. Such findings provide important evidence regarding the factors that influence decision making, helping to facilitate greater understanding of these processes, and to develop interventions of supportive materials for both family members and staff.

Two review questions focused on the impact of decision making on family members and the person with dementia. The review identified a number of outcomes for people with dementia and their surrogate decision makers. Feelings of comfort and confidence were not necessarily affected by increased information to assist decision making;[27] however, one study found less decisional conflict for those using a decision aid.[20] Outcomes for the person with dementia reported in the studies focused on the outcomes of treatment decisions made by family. Two studies reported outcomes for the person with dementia, both relating to tube placement. It is interesting to note that in both studies, negative outcomes including reduced quality of life were reported; however, the family decision makers reported that they felt they had made the right treatment decision.[26,28] Therefore, findings regarding outcomes were limited and mixed. Overall, however, family members experienced some uncertainty or conflict in decision making, but tended not to question their decisions. This suggests a need for support for families to make

decisions with which they feel confident, and which also reflect the best interests and best outcomes for the person with dementia. This reflects the lack of support and information available to proxies in their role that has been identified in the literature.[17] There is also clearly a need for further investigation of the value of decision aids and specific decision interventions before broader conclusions about their utility for practice can be drawn.

One review question concerned the processes family decision makers use. The review more generally identified information and other factors family include in their decision, specifically information about their relative's wishes. The studies revealed that family decision makers had variable levels of knowledge about their relative's wishes. These findings reflect the debate in the literature about family members' ability to correctly identify the wishes of the person receiving care.[51,52] Even when their relative's wishes were explicit, the use of this information to guide decisions varied.[22,24,27,28] The qualitative component of this review found that family members also use other information to guide decisions, including indicators of health, quality of life, or illness.[15] However, surrogate decision makers displayed different degrees of knowledge about treatment options being considered.[21,27] Given that family members are often considered to be the best placed to communicate the wishes of the person with dementia, regarding health and treatment issues, these findings highlight the importance of information and communication – between people with dementia and their families, and between families and staff in residential care – regarding treatment options, outcomes of treatment, and the wishes of the person with dementia. However, they also highlight the importance of supporting families in making decisions that reflect these wishes, and which reflect the best outcomes for the person with dementia.

The quantitative data reviewed here therefore provided some indication of the degree to

which families are involved in decision making and the variables that are related to decision making, as well as the identification and measurement of some key outcomes for both family members and their relatives with dementia. Taken together, these findings suggest some key future directions for research and some practice issues requiring attention; however, it is notable that overall there was much inconsistency in both measurement and findings. Whilst this highlights potential for future research in this area, as noted earlier, it limited the conclusions that could be drawn.

Limitations of the review

Whilst the full review incorporated both qualitative and quantitative studies, these have been separated for publication in order to ensure the fullest possible consideration of the data. The qualitative findings in the companion paper also in this journal provide a more in-depth range of information about the processes behind decision making, the experience of decision making, and the range of roles and relationships, and other key factors that vary between families. The quantitative findings presented here give us an indication of the degree to which families are involved in decision making, some of the variables that are associated with their decisions, and some key outcomes, all of which provides another dimension to the issues that need to be considered in developing relationships between facility staff and family members that support genuine collaboration in such activities. This paper, together with the qualitative findings paper, provides a comprehensive account of the current evidence associated with family involvement in decision making for people with dementia living in residential care.

As with the qualitative component of this review, the focus of this paper was on family decision making for people with dementia in the context of residential care; hence, evidence regarding community settings was deliberately excluded. Further review of decision making in

community settings could provide greater insights into the decision making process for family members. Additionally, although there were some foreign language studies in this area, this review was restricted to papers written in English, which could have affected the findings.

Some limitations of the studies themselves were also identified. While each of the studies provided quantitative data there was no consistency in reporting or the use of standardised instruments; therefore, no meta-analysis of pooled data was possible. One study[19] was excluded as it did not meet criterion 2 (Were criteria for inclusion in the sample clearly defined?). All other studies were considered to be of sufficient quality for inclusion. It was noted, however, that none used a random sample, although the RCT used random allocation, and whilst confounding factors were generally identified, these were not often discussed or addressed explicitly. These issues were not considered essential for quality assessment; nevertheless, they highlight some methodological concerns for quantitative research in this field. It was further evident that methods were largely based on self-report and many of the findings reported were descriptive, with heavy reliance on the reporting of percentages. Statistical analysis was usually Chi-square analysis. More complex relationships were rarely explored in the studies and the lack of standardised, consistent measurement and reporting may have contributed to the overall inconsistency in findings which limited the conclusions that could be drawn.

From the methodological critique of these studies, five key implications for future research in this area can be identified. These are presented below in order of importance for their potential contribution to this body of research. First, the papers identified in this review focused on medical and treatment decisions. Further studies could address other domains of care such as the psychosocial, spiritual, and emotional domains. Second, both the qualitative and quantitative reviews identified a need to explore the variation in surrogates' knowledge and in the use of

knowledge about their relative's wishes. Third, across the reviewed studies, there was a great deal of inconsistency and variation regarding family members' decision making and the role that they take in this process. Future research could explore and examine the reasons behind family members' variation in decision making. The inconsistency in the rate, and levels of understanding, of family involvement in decision making highlights a potential disparity between espoused ideals of person-centred care and the practice of such policies. This signals an avenue for further investigation, particularly with regard to the development of aged care policies and their implementation in residential care contexts, to ensure that practices such as including family members and other proxies in decision making are, in fact, put into place. Only one mixed method study was identified in the review; further mixed method studies, which allow for exploration of both the patterns in decision making and rates of involvement and the experience of decision making processes would provide useful insights into the complexity of decision making. Fourth, as the review findings show, surrogates' level of comfort or confidence in decisions may vary; however, even when positive outcomes are not evident for the person with dementia, the surrogate may still report satisfaction. Research could be conducted into why this incongruence between satisfaction and outcomes occurs. Fifth, only two intervention studies targeting decision making were included in the review, with few identified in the searches; therefore, no conclusions can be drawn about interventions such as decision aids. The randomised controlled trial included, however, demonstrated some potential for the use of interventions such as decision aids. Future studies should explore the potential of such tools, and the conditions or factors affecting their usefulness.

Conclusion

The process of involving family members in decision making on behalf of people with dementia in residential care is evidently complicated. Given the complexity and multiple variables that affect surrogate decision making, greater attention is needed both in research and in practice, to facilitate this process. This could result in greater support for family members during a difficult process, particularly to help ensure their involvement, and to help them ensure that their relatives' wishes, preferences, and values are taken into account in the care that they receive.

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Table 1. Key words for literature search

Setting: residential facility OR residential care OR nursing home OR aged care home OR long term care OR home for the aged OR residential aged care OR elderly care OR aged care facility OR care home;
Population: elderly OR frail elderly OR aged OR older adult OR older person OR older people OR care resident* OR resident* OR elder*; dementia OR alzheimer* OR dement* OR alzheimer* disease OR cognitive impairment OR diminished capacity OR dementia, multi-infarct OR dementia, vascular OR impaired capacity OR Creutzfeldt–Jakob Syndrome OR Lewy Body Disease OR Wernicke* OR Korsakoff* OR Huntington* OR Progressive Supranuclear Palsy OR Pick's Disease OR Binswanger*; family OR proxy OR family proxy OR spous* OR child OR daughter OR son OR relative OR partner OR surrogate;
Phenomena of interest: decision* OR decision-making OR plan* OR advance care planning OR advance care plan OR advance health directive OR advance directive OR care plan OR collaborative decision making; involve* OR engage* OR participat* OR collaborat* OR includ* OR inclus*.
Methodology: rct OR "random allocation" OR "randomi?ed control trial" OR "comparative stud*" OR "interrupted time series" OR "clinical trial" OR "prospective stud*" OR "study design" OR "evaluation research" OR "controlled stud*" OR "cohort" OR "case control" OR "interrupted time series" OR "experimental stud*"

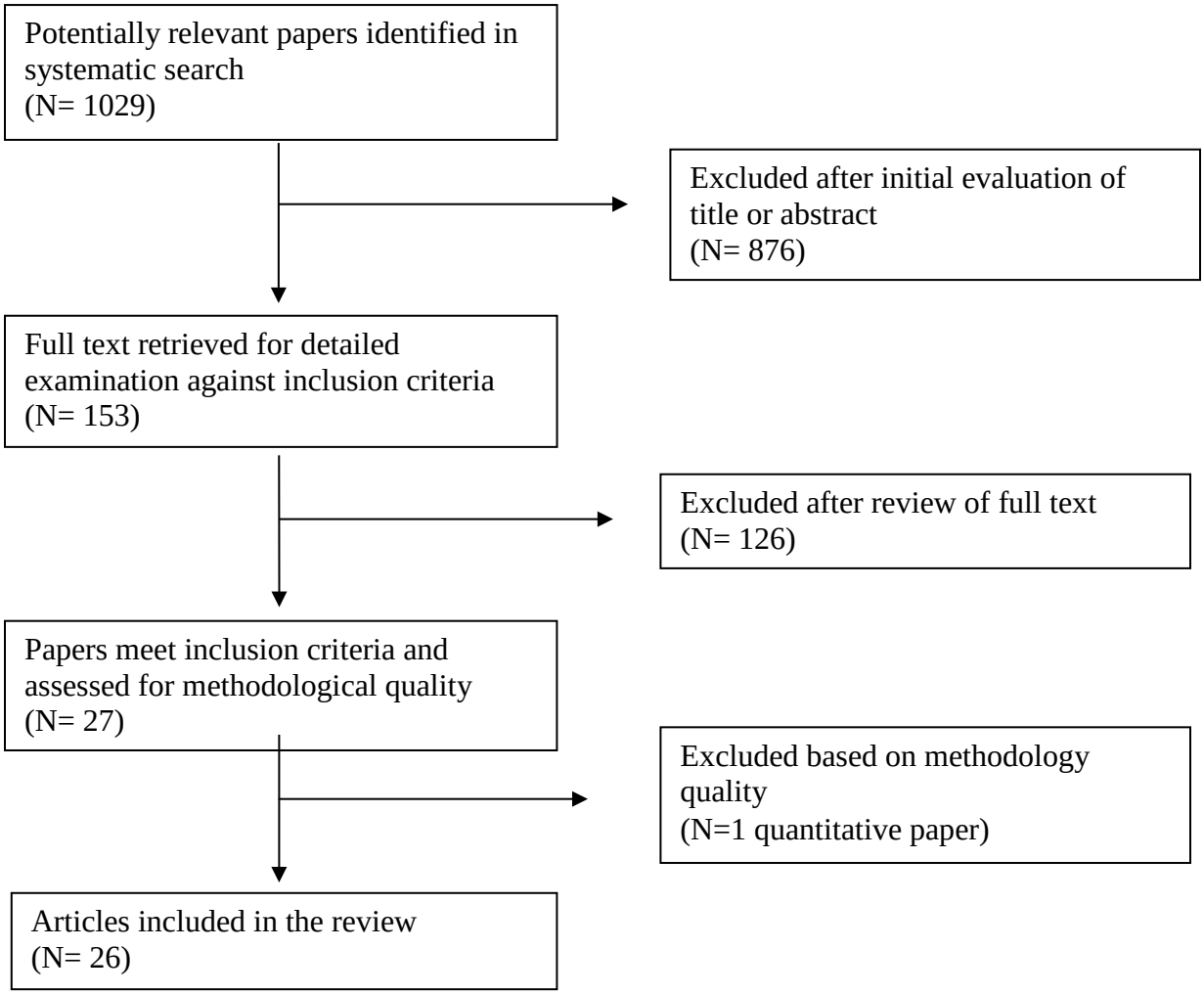

Figure 1: Selection of studies

JBI Critical Appraisal Checklist for Descriptive / Case Series

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

		Yes	No	Unclear	Not Applicable
	1. Was study based on a random or pseudo-random sample?	☐	☐	☐	☐
*	2. Were the criteria for inclusion in the sample clearly defined?	☐	☐	☐	☐
	3. Were confounding factors identified and strategies to deal with them stated?	☐	☐	☐	☐
*	4. Were outcomes assessed using objective criteria?	☐	☐	☐	☐
*	5. If comparisons are being made, was there sufficient descriptions of the groups?	☐	☐	☐	☐
	6. Was follow up carried out over a sufficient time period?	☐	☐	☐	☐
	7. Were the outcomes of people who withdrew described and included in the analysis?	☐	☐	☐	☐
*	8. Were outcomes measured in a reliable way?	☐	☐	☐	☐
*	9. Was appropriate statistical analysis used?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

*Criteria considered essential in quality appraisal

Figure 2. Appraisal instrument for methodological quality of descriptive studies (adapted from JBI-MAStARI)

JBI Critical Appraisal Checklist for Randomised Control / Pseudo-randomised Trial

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

		Yes	No	Unclear	Not Applicable
	1. Was the assignment to treatment groups truly random?	☐	☐	☐	☐
	2. Were participants blinded to treatment allocation?	☐	☐	☐	☐
	3. Was allocation to treatment groups concealed from the allocator?	☐	☐	☐	☐
*	4. Were the outcomes of people who withdrew described and included in the analysis?	☐	☐	☐	☐
	5. Were those assessing outcomes blind to the treatment allocation?	☐	☐	☐	☐
*	6. Were the control and treatment groups comparable at entry?	☐	☐	☐	☐
*	7. Were groups treated identically other than for the named interventions	☐	☐	☐	☐
*	8. Were outcomes measured in the same way for all groups?	☐	☐	☐	☐
*	9. Were outcomes measured in a reliable way?	☐	☐	☐	☐
*	10. Was appropriate statistical analysis used?	☐	☐	☐	☐
		☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info. ☐

Comments (Including reason for exclusion)

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*Criteria considered essential in quality appraisal

Figure 3. Appraisal instrument for methodological quality of RCTs (adapted from JBI-MAStARI)

JBI Critical Appraisal Checklist for Comparable Cohort/ Case Control

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

		Yes	No	Unclear	Not Applicable
	1. Is sample representative of patients in the population as a whole?	☐	☐	☐	☐
	2. Are the patients at a similar point in the course of their condition/illness?	☐	☐	☐	☐
	3. Has bias been minimised in relation to selection of cases and of controls?	☐	☐	☐	☐
*	4. Are confounding factors identified and strategies to deal with them stated?	☐	☐	☐	☐
*	5. Are outcomes assessed using objective criteria?	☐	☐	☐	☐
*	6. Was follow up carried out over a sufficient time period?	☐	☐	☐	☐
	7. Were the outcomes of people who withdrew described and included in the analysis?	☐	☐	☐	☐
*	8. Were outcomes measured in a reliable way?	☐	☐	☐	☐
*	9. Was appropriate statistical analysis used?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info. ☐

Comments (Including reason for exclusion)

_____

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*Criteria considered essential in quality appraisal

Figure 4. Appraisal instrument for methodological quality of cohort studies (adapted from JBI-MAStARI)

Table 2. Included studies

Study	Methods	Study findings
Cogen *et al*., 1992	Observational, Self-administered mailed questionnaire 102 primary family contacts for people with dementia in two nursing homes in the USA <u>Participants</u> Residents: Mean age - 85.2 years, Gender - 79.3% women Surrogates: Mean age - 62.1 years, relationship - mostly adult daughter; 61.8% adult child; 12.7% spouse; 12.7% niece/ nephew; 11.8% other, average education - Golden Supper Club surrogates 13.2 years vs Philadelphia Geriatric Center surrogates 14.2 years (P<.05) <u>Main outcomes</u> • Identification of function of ventilator and gastrostomy tube and purpose of CPR • Experience four specific medical interventions • Acceptance of specific medical interventions for the resident in five hypothetical, clinical situations • Reasons for their decisions	• 100% correctly identified function of gastrostomy tube • 89.1% correctly identified function of ventilator • 84.2% correctly identified role of CPR • 75.5% correctly identified all interventions • 85.3% had experience of at least one intervention <u>Accept or reject medical intervention (hypothetical)</u> • 14.7% - treatment in all situations • 11.8% - no treatment in all situations • 63.4% - agree to hospitalisation for pneumonia • 75.2% - agree to ICU admission for worsening sepsis • 43.6% - agree to mechanical ventilation for resp. failure • 35.4% - agree to tube feeding • 31.6% - agree to CPR • Of those rejecting CPR, 86.3% agreed to transfer to ICU • 76.5% reached a decision for all five situations <u>Reasons for decisions</u> • 3.1% - solely on past statements by the resident • 30.6% - personal views • 5.1% - assumptions re what the resident would choose • 61.2% - combination of factors • 69.7% - No use of previous statements by the patient • Mean positive treat responses = 2.46 (maximum of 5). • Positive correlation between male sex and a positive treat response, r =.21, P<.05. • No significant effect of surrogate age, education, or previous experience with an intervention
Cornegé-	Retrospective, Structured interviews	• 17% - Physicians felt pressured to prescribe APDs

Study	Methods	Study findings
Blokland *et al*., 2012	Participants 27 physicians for 37 cases in which APDs for BPSD in 23 nursing homes in the Netherlands: Mean age - 47 (SD 10), Mean years NH experience - 12 (SD 9), Gender - 48% female Primary responsible nurses: Mean age - 35 (SD 9), Mean years NH experience - 9 (SD 7), Gender - 86% female. Primary family caregivers: Relationship - Child 62%; Spouse 16%. Main outcomes • Pressure to prescribe APDs • Initiator of decision • Weight of opinion in decision • Informed consent • Perception of reason for prescription • Probability of effectiveness	• Felt pressured by nurses - 86% of cases • Felt pressured by family - 17% of cases. Initiator of option to prescribe • Nursing staff - 67.6% of cases • Physician - 13.5% of cases • Family - 10.8% of cases • Colleague physician - 8.1% of cases Opinion bearing most weight according to physicians • Physicians - 67.6% of cases • Nurses - 16.2% of cases • Family - 5.4% of cases • Other professionals - 10.8% of cases Caregiver experience of decision making • 44% felt sufficiently informed about the side effects • 16% not consulted about the prescription • 84% felt opinion was weighted sufficiently • 19% felt opposed to the prescription • 62% supported prescription (compared with 8% of physicians against, 81% supporting; 8% of nurses against, 89% supporting) • Estimated success rate of treatment comparable among physicians, nurses, caregivers (50.3%, 52.8%, 55.3%).
de Boer *et al*., 2011	Retrospective, Questionnaire Participants 434 elderly care physicians in the Netherlands No demographic data provided Main outcomes	• NH policy regarding euthanasia discussed with relative(s) or representative(s) in 95.5% of cases. Initiator of discussion • Resident - 4.5% of cases • Physician -28.6%, • Resident's representative - 28.6% • Other relatives - 27.6% • Other healthcare professionals - 7.6%

Study	Methods	Study findings
	• Discussion of the advance directive for euthanasia and the nursing home policy • Wishes of relatives	<u>Relatives' preferences</u> • 16 (of 110) wanted adherence to advance directive (AD) for euthanasia • unspecified no. wanted physician not to comply with AD • disagreement between relatives - 6.4% • relative had no opinion - 1.8% • relative wanted limitation on life-sustaining treatments - 62.7% • 4.5% of physicians cited relatives not wanting euthanasia performed as a main reason for not adhering to AD
Givens *et al*., 2009	Prospective cohort, Reviews of medical records; interviews with nursing staff; telephone interviews with HCPs <u>Participants</u> NH residents with advanced dementia and their HCPs (Proxies) in 22 nursing homes, USA 323 dyads HCPs: Mean age - 57.5, 62.6% Female, Ethnicity – 93.5% White, 75.6% married, 61.8% College or greater, 26% not resident's child NH Residents: Mean age – 84, 91.1% female, 94.3% white, 18.7% married, 43.9% lived on special dementia unit Baseline mean length of stay - 192 weeks <u>Main outcomes</u> • Medical decision making: Decisions made	<u>HCP and resident characteristics</u> • 83.6% of HCPs felt they understood medical aspects of advanced dementia • 74.1% believed dementia was a terminal illness • 96.6% felt comfort care was goal of treatment • 50.4% of HCPs spent at least 15 mins discussing advance directives with NH provider at admittance <u>Decisions and satisfaction with decision-making:</u> • 123 HCPs had made at least one decision • 232 decisions total - eating/ drinking problems (27.2%), infections (20.7%), hospitalisation 3.9%), pain (12.9%), shortness of breath (8.2%), behavioral issues (6.9%), cancer (3.0%), other (17.2%) • HCPs who made medical decisions were younger (M = 57.5y vs 61.4, p=.003), more likely to be married (75.6% vs 63.0%, p=.02) • Total DSI score Mean = 78.4 (SD = 19.5) • 12-item decision-making process subscale mean significantly lower than mean for the 3 item decision subscale (76.7 ± 21.2 vs 85.5 ± 16.4; p<.001) <u>DSI ratings</u> (agree or strongly agree) • 93% satisfied their opinion was important • 95% the right choice was made • 96% satisfied with the decision made • 94% had enough input in the treatment decision

Study	Methods	Study findings
	by HCPs, recorded at quarterly and 2-month post death interviews • Satisfaction with medical decision making: • Decision Satisfaction Inventory (DSI) • HCP and resident characteristics including demographic data, years as HCP and other relationship variables, beliefs about dementia and their relative's illness, and treatment goals • Communication with healthcare professional about advance directives • Medical Outcomes Study 12-item Short Form Survey (SF-12) • Bedford Alzheimer's Nursing Severity Subscale16 (BANS-S) • Symptom Management at End-Of-Life in Dementia scale16 (SM-EOLD); • Quality of Life in Late-Stage Dementia17 (QUALID); Test for Severe Impairment18 (TSI).	• 85% received enough information about the problem • 87% adequately informed about the treatment • 10% relied too much on the doctor's opinion <u>DSI ratings</u> (excellent or very good) • 78% treatment decision • 70% primary care provider (PCP)'s personal interest • 74% PCP's attention given to their opinion • 64% PCP's reassurance and support • 68% amount of info. about problem and treatments • 71% explanation of treatments • 62% time spent with PCP • 64% amount of help from PCP in making the decision Lowest levels of satisfaction (fair or poor rating) given to: • PCP's reassurance and support (19%) • info. received about problem and treatments (15%) • time with PCP (15%) Variables associated with greater DSI scores at p=.1 • HCP not the resident's child • HCP lived with resident before NH admission • HCP visited resident more than 7 hours per week • higher scores on the HCP SF-12 mental subscale • goal of treatment was comfort care • resident lived on a special care unit • longer resident length of NH stay • higher SM-EOLD score (greater resident comfort) • do-not-hospitalise order <u>Multivariable linear regression</u> • higher DSI scores associated with HCP not being a child of the resident (beta = 7.10, p = .02), the resident living on a special care unit (beta = 9.48, p = .002), and higher SM-EOLD score (beta = 0.49, p = .004).

Study	Methods	Study findings
Hanson *et al*., 2011	RCT Intervention: Structured decision aid - information about dementia, feeding options and outcomes, advantages, and disadvantages of FTs and assisted oral feeding, feeding for comfort near end of life and surrogate's role in decisions. Control surrogates received usual care. Participants Resident's guardian, healthcare PoA or primary family contact in 24 nursing homes, USA. 127 intervention and 129 control participants Residents: Intervention - Mean age = 85.2, 79% female, 67% widowed, 67% white, 83% Protestant. Control – Mean age = 85.3, 76% female, 67% widowed, 73% white, 71% Protestant Surrogates: Intervention - Mean age = 59.3, 68% female, 67% white, 75% Protestant, 45% very religious, Relationship: 7% spouse; 48% daughter; 20% son; 26% other Control – Mean age = 58.7, 58% female, 73% white, 68% Protestant, 47% very religious, Relationship: 9% spouse; 43% daughter; 29%	• decisional conflict same at baseline • at 3 months intervention group had significantly lower scores on the Decisional Conflict Scale than surrogates receiving usual care (1.65 vs 1.97, $p < .001$) and lower scores on each subscale. • both groups experienced reduced decisional conflict over 3 months of follow-up • significantly greater reduction in conflict for intervention group (-0.60 vs -0.13, $p < .001$). • after review of decision aid intervention group had higher mean knowledge scores than controls (16.8 vs 15.1, $p < .001$) and expected fewer benefits from tube feeding (2.3 vs 2.6, $p = .001$) • both groups reported feeling somewhat/ very involved in feeding treatment decisions (no difference, 83% vs 77%, $p = .18$) • over the 3 months, intervention group were more likely than controls to have discussed feeding treatments with a physician, nurse practitioner, or physician's assistant (46% vs 33%, $p = .04$). • no difference in discussions with other nursing home staff (64% vs 71%, $p = .42$). • decisional regret at 3 months M = 11.9 intervention, 14.3 control (low) • satisfaction at 3 months M = 1.61 intervention, 1.66 control (high) • after 3 months, residents in intervention group more likely to receive dysphagia diet (89% vs 76%, $p = .04$) • after 3 months, trend toward greater use of specialised staff assistance for feeding (20% vs 10%, $p = .08$). • no differential effects of intervention for surrogate race or religiosity Chart reviews • No difference btw intervention and control in FT placement ($p = .34$), • No difference btw intervention and control in orders not to tube feed ($p = .41$). • Weight loss less common at 9 months for residents in intervention group (6% vs 16%, $p = .01$).

Study	Methods	Study findings
	son; 20% other <u>Main outcomes</u> • Decisional Conflict Scale • Knowledge about dementia and feeding options • Expectation of Benefit Index. • Frequency of discussion about feeding options - surrogate report • Satisfaction with Decision Scale • Decisional Regret index • Resident demographics • MDS activity of daily living scale • MDS prognostic risk score for advanced dementia • MDS variables for chewing or swallowing; weight loss or poor intake of meals • Nursing, physician, speech therapy, dietary notes • Use of feeding treatments • Chart reviews- resident weight loss, death	• No adverse effects of intervention identified • No difference between intervention and control in mortality at 3 months (6% vs 9%, p = .58) and 9 months (27% vs 29%, p = .69).
Kwok *et al*., 2007	Observational, questionnaire via face–to-face interview Presented scenario of critical illness or coma <u>Intervention</u>: Explanation of unfavourable outcomes of treatment	<u>Importance of in decision making on life-sustaining treatments</u> • Patient's wish - 35% great importance; 37% some importance; 28% no importance. • Doctor's opinion - 96% great or some importance • Own opinion - 92% great or some importance • Other family/ friend's opinion - 75% great or some importance. <u>Rating of relative's quality of life</u> • 35% good

Study	Methods	Study findings
	Participants 51 ethnic Chinese family caregivers in three nursing homes, one day care centre, one psychogeriatric and four long-term care wards Patients: 63% female, 35% aged 50-79; 65% aged 80+, 73% <3 years education; 16% primary school; 8% secondary school; 4% tertiary, 84% nursing home residents. Family caregivers: 65% female, 49% aged 20-49; 49% aged 50-79; 2% aged 80+, 13% <3 years education; 22% primary school; 41% secondary school; 22% tertiary, Relationship with patient - 18% spouse; 63% offspring; 20% other Main outcomes • Knowledge of CPR and tube feeding • Quality of life of the person with dementia • Caregiver's anticipated decisions for four treatments in two hypothetical situations • Comfort and certainty in making treatment decisions • Basis for making the decision, i.e. perceived importance of the patient's own wishes, doctors' opinions, observed norms and reasonableness informing the decision	• 22% fair • 43% poor Discussion of treatment options • 5 caregivers asked by doctors to discuss CPR and tube feeding. • 8% of family caregivers discussed these with their relative • 4% of the people with dementia had expressed own wishes about future medical treatment Knowledge about life sustaining treatments • 59% unable to name any feature of CPR • 26% unable to name any feature of tube feeding • 0 able to name more than three features of CPR • 55% unable to name more than 3 features of tube feeding Treatment decisions • More likely to forgo treatments in irreversible coma vs critical illness [CPR (χ^2 = 9.22, d.f. = 1, P < 0.01), artificial ventilation (χ^2 = 15.59, d.f. = 1, P < 0.01), tube feeding (χ^2 = 7.74, d.f. = 1, P < 0.01), antibiotics (χ^2 = 6.61, d.f. = 1, P < 0.01)]. • After information about clinical outcomes of CPR, four (8%) changed their minds and agreed to forgo CPR in event of critical illness (ns) and six (12%) changed their minds and agreed to forgo CPR in event of coma (p < 0.05, McNemar test) • After information about clinical outcomes of tube feeding, four (8%) changed their minds and agreed to forgo tube feeding in event of critical illness (ns) and seven (14%) changed their minds and agreed to forgo tube feeding in event of coma (p < 0.01 p, McNemar test). • NH residence of patient, higher education of family caregivers, and financial burden due to patients' illness related to decisions to forgo or accept LST (r ranged from 0.277 to 0.339, p < 0.05) • Financial burden predicted family caregivers' inclination to forgo antibiotics in both critical illness (OR 2.06, 95% CI 0.98–4.34) and irreversible coma

Study	Methods	Study findings
		conditions (OR 2.01, 95% CI 1.09–2.69) • Financial burden predicted family caregivers' inclination to forgo tube feeding in irreversible coma (OR 2.03, 95% CI 1.11– 3.71) • NH residence predicted family willingness to forgo artificial ventilation in critical illness (OR 5.33, 95% CI 1.08–26.36) <u>Certainty and comfort</u> • Among those who decided to forgo treatments in critical illness, between 43% and 55% were certain about their decisions, and between 72% and 90% were comfortable with their decisions • Among those who decided to forgo treatments in coma, between 41% and 50% were certain, and between 78% and 85% were comfortable • Significantly more comfortable with forgoing than choosing treatments in coma scenario (χ^2 = 5.303, 4.293, & 4.097, d.f. = 1, P < 0.05 for CPR, artificial ventilation and antibiotics respectively) • Information about clinical outcomes did not influence certainty or comfort
Maust *et al*., 2008	Retrospective, Resident medical record review (MRR); Surrogate interview using a structured questionnaire <u>Participants</u> N = 123, n = 100 Three long term care facilities in U.S.A. Residents: 41% female, 85% white, 65% Up through high school graduate; 34% At least one year of college, Mean age = 81.3 (no treatment); 81.2 (treatment) Surrogates: 75% female, 83% white, 37% up through	<u>Treatment decision faced</u> • hospitalisation (73.2%), • surgery (46.3%), • tests (69.1%), • X-rays (57.7%), • treatment for pneumonia (34.1%), • treatment for other infections (53.7%), • feeding tube (FT) (46.3%) • respirator or ventilator (38.2%) <u>Decision made</u> • Most chose treatment for hospitalisation, surgery, tests, X-rays, treatment for pneumonia and other infections • Most chose no treatment for FT and respirator or ventilator *NB. Findings for paper based on decisions regarding hospitalisation and surgery*

Study	Methods	Study findings
	high school graduate; 63% At least one year of college, Mean age = 62.4 (no treatment); 57.5 (treatment) <u>Main outcomes</u> • Surrogate treatment decisions at baseline • Demographic characteristics • Medical status of each resident • Reason for admission • Cognitive impairment - Severe Impairment Rating Scale (SIRS) • Resident quality of life - Alzheimer Disease Related Quality of Life scale and 5-point Likert scale • Communication by involved parties - Communication about end of life care, Presence of an AD or "do not hospitalise" order (DNH), frequency of contact with the • resident as well as with the primary physician, nurses and social worker • Surrogate formal and informal spirituality or religious beliefs • Whether they had participated in dementia caregiver support groups over the previous year • Whether they had helped to make healthcare decisions for adults other than the resident	• White race and older age of surrogate associated with decision to not treat (p = 0.022 and p = 0.046, df = 98). • White race (p = 0.010) and more education of resident (p = 0.041, df = 1) associated with decision not to treat • Trend for males to have received less treatment (ns) • No medical comorbidities associated with not treating – Trend for less treatment in residents with COPD or active heart disease ($p<0.10$, df=1 for both by $\chi 2$) • Admitted to the nursing home for medical complications more likely to have received treatment (p = 0.050, df = 1) • Worse surrogate-rated resident quality of life associated with not providing treatment (p = 0.004, df = 94) • No association between staff discussions about end of life care and not providing treatment • More frequent contact with nurses associated with not providing treatment (p=0.031, $\chi 2$, df=1). • No patients had ADs addressing acute hospitalisation • 40% had DNH orders on their charts • Presence of a DNH order significantly associated with decision to not provide treatment (p,.001, df = 1) • No significant differences in treatment choice by and of the seven items regarding religion and spirituality (p ranging from 0.650 to 0.981, $\chi 2$, *df*=1) • No significant association between past experience making healthcare decisions for another adult and treatment decisions (p=0.677, $\chi 2$, *df*=1) • Significantly more of those who attended support groups for dementia caregivers chose not to treat (p=0.048, $\chi 2$, df=1) • In logistic regression analysis, resident race and gender significantly associated with not providing treatment (OR = 14.60, CI 1.72–123.77, p=0.014 for white residents and OR = 3.09 , CI 1.25–7.67, p=0.015) for male residents) • In second model, white race (OR 9.53, CI 1.09–83.58, *p*=0.042) and presence

Study	Methods	Study findings
		of DNH order (OR 8.17, CI 3.10–21.51, p= <0.001) significantly associated with not providing treatment
Pasman *et al*., 2004	Retrospective, Questionnaire directly after the decision was made <u>Participants</u> For 178 nursing home patients with dementia: 178 (100%) cases, NHPs filled out a questionnaire 167 (94%) cases, Nurses filled out a questionnaire 128 (72%) cases, Family members filled out a questionnaire 32 Nursing homes in the Netherlands No demographic data provided for NHPs, nurses or family members. Patients: scarcely or no longer ate or drank, and a decision was made to start or forgo ANH; Mean age - 85.4, 79 female, Dementia type - 43 Alzheimer; 22 Vascular; 15 Mixed; 20 Undiagnosed, Degree of competence at time of decision - Fully competent 2; Not fully competent 12; Incompetent 86 <u>Main outcomes</u> • Number of discussions • Degree of influence participants had on the	<u>Advance care planning</u> • Agreements made in 68% of cases • More often to forgo (64%) than start treatment (44%) • More common to forgo vs agree to hospitalisation (48% vs 20%), • More common to forgo vs agree to ANH (42% vs 20%) • More common to forgo vs agree to resuscitation (42% vs14%) • More common to forgo vs agree to life prolonging treatment generally (29% vs 18%). • More common to agree vs forgo antibiotics (28% vs 3%) • Most common treatments to forgo were admission to hospital, ANH and resuscitation; most common to start were antibiotics, ANH and hospitalisation • Agreements most often made with the children of the patient (78%). Agreements also reported with other family members (17%) and patient's partner (11%) <u>Discussions with family and family influence</u> • NHPs reported discussing decision with the patient's family in 99% of cases • Nurses reported discussing decision with family in 88% of cases; family reported discussing the decision with physicians and nurses less than did NHPs and nurses themselves (87% and 65%) • Majority of NHPs (70%), nurses (40%) and family (46%) reported that family had considerable influence • More nurses (54%) and family (39%) than physicians (3%) reported that family influence was decisive • If NHPs had considered ANH, "wishes of the patient's family" was one of their stated reasons <u>Decision maker</u> • NHP said they made final decision (with or without others) - 97% of cases

Study	Methods	Study findings
	decision making process and final decision • Evaluation of the decision making process • Patient characteristics • Advance care planning • Considerations to start or forgo ANH • Primary aim of forgoing ANH	• NHP said family made final decision (with or without others) - 64 % of cases • Family said they made final decision (with or without others) - 78% of cases • Family said NHP made final decision (with or without others) - 57% of cases • Nurse said they made final decision (with or without others) - 26% of cases • Nurse said family made final decision (with or without others) - 92% of cases • Family said nurse made final decision (with or without others) - 28% of cases • Family members said that they made the final decision alone - 33% of cases • NHP said they made final decision without mentioning others – 31% of cases • 98% reported consensus about final decision <u>Assessment of process</u> • Family satisfied with the openness in the decision -making process (21 cases) satisfied with information received from the professional staff (18 cases) satisfied with opportunity to give their opinion (14 cases) • 6 of 24 family members dissatisfied with pressure of short time for decision • 5 of 86 NHPs dissatisfied that had not discussed ANH with family in advance
Rurup *et al*., 2006	Observational, Questionnaire <u>Participants</u> 107 physicians from 32 nursing homes in three regions in the Netherlands 136 relatives 178 nurses (148 completed nurse questionnaires included) Physician characteristics: 51% male, mean age = 41, 55% report no religious beliefs; 17% report religious beliefs that do not influence ANH decision-making; 28% report religious beliefs that do	• Findings reported significant (Chi-square); no values given • More nurses 35% and relatives (47%) than physicians (15%) fully agreed refusal of food/ drink should be respected. – Relatives agreed more often if relative had more pain and lower comfort when decision was made • Physicians (89%) agreed more often than nurses (57%) and relatives (49%) that "Forgoing artificial nutrition and/or hydration in patients with dementia is almost always followed by a peaceful death". • All agreed that "On admission, the treating physician should routinely ask the patient or the patient's family about any possible wishes concerning the end of the patient's life." More relatives (78%) than nurses (61%), and more nurses than physicians (44%) fully agreed • 78% of the nurses and 88% of the relatives, but only 37% of the physicians agreed that "An advance directive should always be followed".

Study	Methods	Study findings
	Nurses: 17% male, mean age =34, 42% report no religious beliefs; 36% report religious beliefs that do not influence ANH decision-making; 21% report religious beliefs that do Family: 38% male, mean age = 57, 38% reported no religious beliefs; 42% reported religious beliefs that do not influence ANH decision-making; 20% reported religious beliefs that do, Relationship with the patient - Partner 8%; Child 64%; Other 27%. Patients: Advance directive - 7%, Decision ANH (starting ANH) 7%, 28% reported to have no religious beliefs; 61% reported to have religious beliefs that did not influence ANH decision-making 11% reported to have; religious beliefs that did influence ANH decision-making. <u>Main outcomes</u> • Attitudes towards ANH concerning nursing home patients with dementia • Attitudes towards advance directives • Attitudes towards hastening the death of patients in the advanced stages of dementia • Attitudes towards self-determination and euthanasia based on an advance euthanasia directive • Attitudes towards policy concerning	– Of the 10 patients who had an advance directive, 9 relatives agreed with this statement • Relatives (64%) agreed more often than the physicians (23%) and nurses (27%) that ‘‘Patients in the advanced stages of dementia are totally unable to indicate when they no longer want to live’’ – Relatives who stated that their religious beliefs or those of their relative influenced decision-making agreed less often (41% vs 21%) • Nurses (55%) agreed less often than physicians (72%) and relatives (79%) that ‘‘It is almost always best not to prevent the death of patients in the advanced stages of dementia’’ – Partners and children agreed less often with this than people related in other ways (73% vs 94%) • The majority of each agreed (78–84%) that ‘‘Everyone has the right to decide about his/her own life and death’’ – Physicians (34%) less often fully agreed with this statement that nurses (63%) and relatives (62%) – In all groups, a trend towards people who were more religious agreeing less often with this statement • Relatives (90%) agreed more often than nurses (57%), and nurses agreed more often than physicians (16%) that ‘‘Euthanasia is permissible for incompetent patients if they signed an advance euthanasia directive when they were still competent’’ – Trend towards people who were more religious agreeing less often – Relatives of patients who had an advance directive all agreed – Relatives of patients with an advance euthanasia directive fully agreed • Most physicians, nurses and relatives agreed (87–95%) that ‘‘In decisions to forgo treatment the well-being of the patient always outweighs the well-being of the patient’s relatives’’ – Relatives (87%) more often fully agreed with this statement than physicians (50%) and nurses (64%)

Study	Methods	Study findings
	forgoing treatment	• Most in all groups agreed (72– 75%) that ‘‘There should be guidelines for decisions concerning forgoing possible life-prolonging treatment’’ – Physicians (28%) fully agreed less than nurses (51%) and relatives (62%)
Somogyi-Zalud *et al*., 2001	Retrospective, 16-item structured questionnaire, Resident’s medical chart <u>Participants</u> 50 residents and surrogates in 2 NHs Residents: on tube feeding for at least 6 months and lacked decision making capacity at the time of feeding tube placement, Ethnicity – 52% non-Hispanic whites; 40% African-Americans; 8% Hispanic, median age 89.5 years, 90% female, 72% with diagnosis of dementia, 8% with advance directive stating wishes re feeding tube Surrogates: 52.1% non-Hispanic whites; 39.6% African-Americans; 8.3% Hispanic, 64% female, median age - 57.0 years, Relationship to resident - 58% child; 38% relative or friend; 4% spouse, 14.3% had prior experience with tube feeding <u>Main outcomes</u> • Weight • Albumin level • Surrogates’ perception concerning resident’s wishes	<u>Complications of tube placement</u> • Tube displacement (76%) • Vomiting (24%) • Aspiration pneumonia (20%) • Clogged tube (18%) • Tube site infection (10%) • Recurrent fever (8%) <u>Surrogates’ perception concerning resident’s wishes</u> • 10% ever discussed tube feeding with the resident • 8% resident ever clearly stated his/ her wishes • 54% given enough information to make the decision • 24% thought resident would agree to FT • 42% did not know whether resident would agree to FT • 34% comfortable making the decision • Other family members participated in decision - 52% <u>After feeding tube placement</u> • 54% rated resident’s quality of life poor/extremely poor; 24% rated resident’s quality of life good/ very good • 54% agreed FT changed the resident’s quality of life, 48.1% improved/ much improved, and 51.8% worse/ much worse • 78% felt that FT was of overall benefit to the resident • 62% would repeat the decision • 14% would consider removing FT <u>Surrogates’ concerns regarding FT</u> • Greatest concern - medical complications (42% very/ somewhat concerned), followed by impact on quality of life (42% very/ somewhat concerned)

Study	Methods	Study findings
	• Surrogates' attitudes after a minimum of 6 months of feeding tube placement – quality of life of the resident, consider removing the tube feeding, repeat decision for tube feeding, benefit to the resident, change in quality of life of the resident • Surrogates' concerns regarding tube feeding • Complications attributed to tube feeding	Most not concerned about • medical complication of tube feeding (58%) • adequacy of nursing care (68%) • impact on quality of life (58%) • change in body image (88%) • potential for restraint use to prevent pulling (92%) • resident might receive less attention from staff (76%) • resident might be viewed less of a person (92%) • 66% felt concerns addressed properly by staff
Teno *et al*., 2011	Retrospective, Death certificates; Interview with next of kin conducted on average 23.8 months after the nursing home resident's death <u>Participants</u> n = 486 next of kin in 5 US states Decedents: Mean age 87.9, 71.5% female, 85.7% white Respondents: n = 486, 66.6% female, Relationship to decedent - Spouse 8.4%; Child 66.6%; Sibling 3.5%; Other 21.5%, Education - <8th grade 1.1%; Some high school 3.0%; High school graduate 23.2%; Technical school 4.9%; 1-3 years college 25.2%; 4 year college graduate 17.2%; >4 year degree 24.7% <u>Main outcomes</u>	<u>Feeding tube decision-making</u> • 10.75% of residents had feeding tube (FT) inserted • 30.3% of family members stated there was discussion about managing eating problem, decision made to forgo FT, or both • In 58.9% of cases, no discussion about managing eating problems between family and healthcare provider • For residents with FT, no discussion with a healthcare provider before FT inserted in 13.7% of cases • For those without discussion, 91.1% believed that a discussion should have occurred • Primary care physician was involved in discussions in 32.7% of cases in which FT inserted, and 30.8% of cases in which a decision was made for no FT • Discussion lasted less than 15 mins in 41.6% of cases where FT inserted and 23.6% of cases where no FT • Discussion of risks of FT in 49.7% of cases in which FT inserted and 45.5% of cases where no FT • Discussion of benefits in 60.3% of cases in which FT inserted and 50.4% of cases where no FT • Option of hand-feeding discussed in 22.6% of cases in which FT inserted and 40.1% of cases where no FT

Study	Methods	Study findings
	• Feeding tube decision-making - Modified questions from Toolkit of Instruments to Measure End of Life Care • Outcomes of feeding tubes. • Perceptions of quality of end-of-life care	• Physician ‘‘strongly in favour’’ of FT in 38.2% of cases in which FT inserted and 1.4% of cases where no FT • Family felt pressured by physician in 11.2% of cases where FT inserted • Religious beliefs of resident and family influenced decision in 13.6% of cases in which FT inserted • 25.7% stated FT inserted to make feeding easier for staff <u>Outcomes of feeding tubes</u> • Improved resident quality of life (32.9%) • Seeming bothered by FT (39.8%) • Hands/ upper body tied down to prevent pulling FT (25.9%) • Medications to calm and prevent pulling FT (29.2%) • Medication/ tied down to prevent pulling FT (34.9%) • Sent to ED because of problem with FT (26.8%). • Surrogate felt regret about the decision - 23.4% • Surrogate felt it was the right decision - 61.9% • At time of death, FT stopped/ withdrawn - 38.5% – In 66.3% of these, death occurred within 1 week. – 25.5% of respondents distressed during this period • Respondents whose relative died with FT less likely to rate quality of EOL care as excellent in last week of life (adjusted OR 0.42, 95% CI = 0.18–0.97)